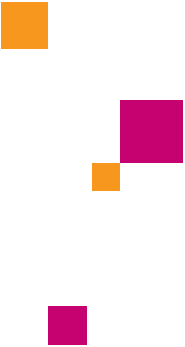



# What You Should Know About Lupus



*Just like snowflakes,  
no two cases of lupus  
are exactly alike...*



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# When it comes to lupus, one size doesn't fit all.

Because lupus is a complex disease with wide-ranging symptoms and manifestations, it is important for people with Lupus to work with knowledgeable physicians and other health professionals. You can learn what you need to know to help you live with the condition by gathering accurate information. Here are some answers to common questions.

## ■ What is lupus?

### *A disease that “attacks” your immune system.*

Your immune system is your body's natural defense against disease. When you have lupus, your immune system has stopped working properly—antibodies that normally protect you against infection are misdirected and attack healthy tissues and organs. This may cause inflammation, injury and pain much like a splinter in your toe causes it to become swollen, tender and red. In lupus, the inflammation occurs inside your body's vital organs and systems. The targets vary from person to person, but most people with the disease have symptoms restricted to only a few parts of the body.

## ■ What are the different types of lupus?

### *Systemic lupus can affect almost any part of your body.*

The most common type of lupus is systemic lupus erythematosus (SLE). It can cause inflammation almost anywhere in your body. You may only have symptoms involving your skin and joints, or you may have inflammation of your joints, lungs, kidneys, blood, organs and/or other tissues. You may have periods of remission with few or no symptoms, and you may also experience “flares” when the disease gets more active.

### *Cutaneous lupus affects your skin.*

There are many different types of lupus skin rashes. Sometimes patients can have a rash without any other manifestations of lupus. One of the common types of skin lupus is called discoid lupus erythematosus (DLE) and is identified by a rash that may appear on your face, neck or scalp, and by hair loss. It is not life-threatening. The rash may be more noticeable when your skin is exposed to sunlight or fluorescent light. About 10% of people with discoid lupus eventually develop systemic lupus, and about 30% of systemic lupus patients will have discoid lupus rashes.

### *Drug-induced lupus can occur from medication.*

A few prescription medicines can create symptoms similar to SLE, but the kidneys and nervous system are not usually affected. Such drugs are hydralazine (for high blood pressure), procainamide (for irregular heart rhythms), and commonly used anticonvulsants (for seizures). Only a very small number of people who take these medications will actually develop the disease. You can take these drugs for a period of time before symptoms appear. After the drugs are stopped, the lupus symptoms will usually disappear after a period of time.

## ■ What causes lupus?

The cause of the disease is unknown. Researchers think genetic, environmental and possibly hormonal factors combine in some way to cause the condition. You can't “catch” lupus from someone else, and it can't be sexually transmitted. While lupus can run in families, it most likely takes external factors to trigger the illness, such as overexposure to ultraviolet rays or certain drugs. Infections, trauma, stress, surgery or hormones may also bring about symptoms of lupus.

## ■ Who is most likely to get lupus?

If you are female you are at greater risk. Lupus may occur in males or females and can happen at any age, but young women between the ages of 15 and 44 are most likely to develop the disease. Some researchers think female sex hormones, especially estrogen, have an effect on the immune system and make females more susceptible to developing lupus. Lupus is more common among African American, Hispanic/Latina, Asian and Native American women.

## Lupus in the U.S.

**It is estimated that approximately 1-1.5 million Americans may have lupus.**

- 90% of these individuals are women.
- Lupus is more common among African American, Hispanic/Latina, Asian and Native American women.
- About 5% of children born to those with lupus will develop the disease.

## ■ What are the most common symptoms?

*Most people with lupus have symptoms in only a few organs.*

If you have not already been diagnosed, the following table may alert you to the possibility of lupus. If you have already been diagnosed, these symptoms may indicate increased activity of the disease, known as a “flare.” You may also have periods of remission when few or no symptoms are present. For most people, lupus can be managed and will affect only a few organs. Others may face serious, sometimes life-threatening problems.

## Lupus Symptoms

- Achy joints (arthralgia)
- Fever over 100 degrees F
- Swollen and painful joints (arthritis)
- Prolonged fatigue
- Skin rashes
- Anemia
- Swollen ankles (kidney involvement)
- Chest pain upon deep breathing (pleurisy)
- Butterfly-shaped rash across cheeks and nose
- Sensitivity to sun (photosensitivity)
- Unusual hair loss
- Abnormal blood clotting problems
- Pale or purple fingers from cold or stress (Raynaud’s Phenomenon)
- Seizures
- Mouth ulcers (often painless, at roof of mouth)

## ■ How is lupus diagnosed?

*No single lab test can tell if you have lupus.*

Many lupus symptoms imitate symptoms of other diseases and often come and go. Your primary care doctor or rheumatologist will use your medical history, a physical exam and many routine as well as special tests to rule out other diseases. Many physicians also use the American College of Rheumatology’s “Eleven Criteria of Lupus” to aid in the diagnosis of lupus. The criteria include symptoms as well as specific laboratory findings that provide information about the functioning of a person’s immune system. In most cases, the diagnosis of lupus is made when four or more of the criteria have occurred at some time.

## The “Eleven Criteria”

1. *Malar rash* – butterfly-shaped rash across cheeks and nose
2. *Discoid (skin) rash* – raised red patches
3. *Photosensitivity* – skin rash as result of unusual reaction to sunlight
4. *Mouth or nose ulcers* – usually painless
5. *Nonerosive Arthritis* – (bones around joints do not get destroyed) in 2 or more joints with tenderness, swelling or effusion
6. *Cardio-pulmonary involvement* – inflammation of the lining around the heart (pericarditis) and/or lungs (pleuritis)
7. *Neurologic disorder* – seizures and/or psychosis
8. *Renal (kidney) disorder* – excessive protein in the urine, or cellular casts in the urine
9. *Hematologic (blood) disorder* – hemolytic anemia, low white blood cell count, or low platelet count
10. *Immunologic disorder* – antibodies to double stranded DNA, antibodies to Sm, or antibodies to cardiolipin
11. *Antinuclear antibodies (ANA)* – positive test in absence of drugs known to induce it.

## ■ Does a positive ANA test mean I have lupus?

*No, the answer is maybe.*

Your immune system is your body’s natural defense against disease. A positive antinuclear antibody (ANA) blood test shows that your immune system is making an antibody (protein) that reacts with components of your body’s cells. This is called autoimmunity and may or may not be harmful to your body. While a positive ANA may be associated with an autoimmune illness like lupus, it does not mean you have the disease. Approximately 20% of the normal population will have a positive ANA test; positive tests are also seen in other conditions, such as thyroid disease, certain liver conditions, and other autoimmune diseases. Before making a diagnosis, your doctor should be able to find objective physical or laboratory evidence of the condition, such as swelling of your joints, protein in your urine, fluid around your lungs or heart, or a positive skin biopsy.

## ■ What is the treatment for lupus?

### *While there is no cure, there are treatments.*

Early diagnosis and appropriate treatment can help manage the symptoms of the disease and lessen the chance of permanent damage to organs or tissue. Once a diagnosis is established, patients are assessed for damage to major organs (central nervous system, kidneys, heart or lungs). Treatment depends on the activity and extent of the disease.

### *Medications may include:*

- **NSAIDS** – nonsteroidal anti-inflammatory drugs to relieve achy joints and arthritis in mild SLE when pain is limited and organs are not affected.
- **Antimalarial drugs** – such as hydroxychloroquine, often prescribed for arthritis or skin problems.
- **Corticosteroids** – such as prednisone, used for major organ involvement. The dosage prescribed will depend on the type of organ involvement, symptoms, and blood-test results.
- **Immunosuppressive agents** – such as azathioprine, methotrexate, cyclophosphamide, cyclosporine, and mycophenolate mofetil. These very potent drugs help control the overactive but misdirected immune system in lupus patients. They help limit damage to major organs and are closely monitored to counter the potentially serious side effects and complications.

### *What you can do:*

- **During a “flare”** – get plenty of rest.
- **When in remission** – exercise to increase joint flexibility and muscle strength.
- **If you are sensitive to sun** – use sunscreen and avoid the sun. If rashes persist, check with your doctor about using a cortisone cream.
- **Relieve stress** – support groups, counseling, talking with friends, family and physicians can be helpful.
- **For fever over 100 degrees F** – call your doctor.
- **Get regular checkups** – these usually include blood and urine tests.
- **Ask questions** – when in doubt, call your doctor.
- **Report any side effects or new symptoms promptly** – help your physician know when a change in therapy might be needed.

### *What is the outlook for people with lupus?*

While there is not yet a cure, research uncovers promising new findings each year. Over the last two decades, better diagnostic techniques and treatment methods have led to more effective management of lupus and its complications. Just twenty years ago, only 40 percent of people with lupus were expected to live more than three years following diagnosis. Now with earlier diagnosis, the latest therapies and careful monitoring, most people with lupus can look forward to a normal lifespan.

## ■ About the S.L.E. Lupus Foundation

The S.L.E. Lupus Foundation, headquartered in New York and Los Angeles, is one of the leading lupus organizations in the United States. For more than 30 years, the Foundation has supported the lupus community through patient education and support services, professional education, public awareness, and funding for lupus research.

A decorative graphic consisting of several colored squares (orange, purple, and pink) and a large orange oval containing the text "Get into the loop.™".

**Get into the loop.™**

This brochure was developed by the S.L.E. Lupus Foundation in consultation with the following medical advisors: Jill Buyon, MD, Richard Furie, MD, and Ellen M. Ginzler, MD, MPH.